

111TH CONGRESS  
1ST SESSION

# S. RES. 241

Designating the period beginning on September 13, 2009, and ending on September 19, 2009, as “National Polycystic Kidney Disease Awareness Week”, and supporting the goals and ideals of a National Polycystic Kidney Disease Awareness Week to raise public awareness and understanding of polycystic kidney disease and the impact polycystic kidney disease has on patients and future generations of their families.

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IN THE SENATE OF THE UNITED STATES

AUGUST 5, 2009

Mr. KOHL (for himself and Mr. HATCH) submitted the following resolution;  
which was referred to the Committee on the Judiciary

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## RESOLUTION

Designating the period beginning on September 13, 2009, and ending on September 19, 2009, as “National Polycystic Kidney Disease Awareness Week”, and supporting the goals and ideals of a National Polycystic Kidney Disease Awareness Week to raise public awareness and understanding of polycystic kidney disease and the impact polycystic kidney disease has on patients and future generations of their families.

Whereas polycystic kidney disease, known as “PKD”, is 1 of the most prevalent life-threatening genetic diseases in the United States;

Whereas polycystic kidney disease is a severe, dominantly inherited disease that has a devastating impact, in both human and economic terms, affecting equally people of all ages, races, sexes, nationalities, geographic locations, and income levels;

Whereas there are 2 hereditary forms of polycystic kidney disease, with autosomal dominant polycystic kidney disease (ADPKD) affecting 1 in 500 people worldwide, including 600,000 patients with polycystic kidney disease in the United States, according to prevalence estimates by the National Institutes of Health;

Whereas in families in which 1 or both parents have ADPKD there is a 50-percent chance that the parents will pass the disease to their children;

Whereas autosomal recessive polycystic kidney disease (ARPKD), a rarer form of PKD, affects 1 in 20,000 live births and frequently leads to early death;

Whereas in families in which both parents carry ARPKD there is a 25-percent chance that the parents will pass the disease to their children;

Whereas, in addition to patients directly affected by polycystic kidney disease, countless additional friends, loved ones, family members, colleagues, and caregivers must shoulder the physical, emotional, and financial burdens of polycystic kidney disease;

Whereas polycystic kidney disease, for which there is no treatment or cure, is the leading cause of kidney failure resulting from a genetic disease, and 1 of the 4 leading causes of kidney failure in the United States;

Whereas the vast majority of patients with polycystic kidney disease have kidney failure at the age of 53, on average,

causing a severe strain on dialysis and kidney transplantation resources and on the delivery of health care in the United States, as the largest segment of the population of the United States, the baby boomers, continues to age;

Whereas end-stage renal disease is one of the fastest growing components of the Medicare budget, and polycystic kidney disease contributes to the cost with an estimated \$2,000,000,000 budgeted annually for dialysis, kidney transplantation, and related therapies;

Whereas polycystic kidney disease is a systemic disease that causes damage to the kidneys and the cardiovascular, endocrine, hepatic, and gastrointestinal systems;

Whereas polycystic kidney disease instills in patients a fear of an unknown future with a life-threatening genetic disease, and apprehension over possible genetic discrimination;

Whereas the severity of the symptoms of polycystic kidney disease and the limited public awareness of the disease cause many patients to fail to recognize the presence of the disease, to forego regular visits to physicians, and not to receive good health or therapeutic management that would help avoid more severe complications when kidney failure occurs;

Whereas people suffering from chronic, life-threatening diseases, such as polycystic kidney disease, are more frequently predisposed to depression and the resulting consequences of depression because of anxiety over the possible pain, suffering, and premature death that people with polycystic kidney disease may face;

Whereas the Senate and taxpayers of the United States want treatments and cures for disease and hope to see results

from investments in research conducted by the National Institutes of Health and from initiatives such as the National Institutes of Health Roadmap to the Future;

Whereas polycystic kidney disease is an example of how collaboration, technological innovation, scientific momentum, and public-private partnerships can—

(1) generate therapeutic interventions that directly benefit the people suffering from polycystic kidney disease;

(2) save billions of Federal dollars under Medicare, Medicaid, and other programs for dialysis, kidney transplants, immunosuppressant drugs, and related therapies; and

(3) allow several thousand openings on the kidney transplant waiting list;

Whereas improvements in diagnostic technology and the expansion of scientific knowledge about polycystic kidney disease have led to the discovery of the 3 primary genes that cause polycystic kidney disease, and the 3 primary protein products of the genes, and to the understanding of cell structures and signaling pathways that cause cyst growth that has produced multiple polycystic kidney disease clinical drug trials;

Whereas there are thousands of volunteers nationwide dedicated to expanding essential research, fostering public awareness and understanding, educating patients and their families about polycystic kidney disease to improve treatment and care, providing appropriate moral support, and encouraging people to become organ donors; and

Whereas volunteers engage in an annual national awareness event held during the third week of September, making that week an appropriate time to recognize National

Polycystic Kidney Disease Awareness Week: Now, therefore, be it

1       *Resolved*, That the Senate—

2               (1) designates the period beginning on Sep-  
3       tember 13, 2009, and ending on September 19,  
4       2009, as “National Polycystic Kidney Disease  
5       Awareness Week”;

6               (2) supports the goals and ideals of a national  
7       week to raise public awareness and understanding of  
8       polycystic kidney disease;

9               (3) recognizes the need for additional research  
10      into a cure for polycystic kidney disease; and

11              (4) encourages the people of the United States  
12      and interested groups—

13                      (A) to support National Polycystic Kidney  
14      Disease Awareness Week through appropriate  
15      ceremonies and activities;

16                      (B) to promote public awareness of poly-  
17      cystic kidney disease; and

18                      (C) to foster understanding of the impact  
19      of the disease on patients and their families.

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